

Abstract

There is a lack of understanding on how paramedic students develop their knowledge, skills and attitudes to support people living with dementia and their families. This original qualitative study applied focus groups to explore paramedic students' perspectives. First and third year paramedic students were recruited from two ambulance service providers in the South of England. Data were collected during January and February 2017 and three themes emerged: 1) challenges of communication 2) students' negative emotional response, and 3) lack of social care and pathways. Paramedic students did not discuss person-centred approaches to support people with dementia; however they all acknowledge the impact of dementia as unique to each person, their family and situation. Undergraduate paramedic education needs to support the development of students' communication and interpersonal skills. Both university lecturers and placement educators need to provide consistent, clear, detailed information to enable students to support and care for people with dementia and their families.

Keywords

Dementia, paramedic, qualitative, focus groups, education

Introduction

Globally many countries have developed the role of the paramedic through education and undergraduate programmes, which vary within and across countries (Colver et al 2016; Hou et al 2013; Hickson et al 2015). In England national guidelines for paramedic education have been implemented (Brown et al 2016), alongside national standards for paramedic professionalism and a fit to practice register (College of Paramedics, 2015; Heath and Care Professionals Council, 2016).

Paramedic programmes need to respond to the changing needs of society. The world population of people aged 60 years and over has been predicted to increase by 56% between 2015 and 2030 (United Nations, 2015). Dementia is not restricted to those within this age group; however the risk of developing dementia doubles every five years from the age of 65 (Corrada et al 2010; Prince et al 2016). An analysis of four days of data from two counties in England demonstrated that 21.5% of ambulance call outs were to patients with a diagnosis of or documentation suggesting dementia or cognitive impairment (Buswell et al 2016).

Paramedics are the best placed healthcare professionals to support people with dementia and their families through a crisis and to avoid hospital admissions where possible (Evans et al 2014).

However, recent studies have highlighted a lack of education on caring for older adults and people with dementia in undergraduate paramedic programmes (Abbey et al. 2006; Annear et al 2016). The Department of Health (DH) has identified the need for Higher Education Institutes to facilitate learning, knowledge and clinical skills in the area of aged care (DH, 2010), with a view to reconfigure paramedic practice to ensure that care of the aged person becomes key (Ham, 2017).

Undergraduate paramedic education should develop students' clinical and interpersonal skills.

Traditional paramedic programmes have focused on the acquisition of clinical skills and reasoning through clinical placements (Smith, 2016), which has led students to focus on skills such as cannulation and resuscitation (Ross et al 2015), to the detriment of soft skills, such as

communication (Jackson, 2009; Ross et al 2015). This approach has led to patient interactions that are operationalised into a series of sequential events (Halter et al 2011), where some paramedic students experience difficulty with social interactions due to the lack of assessment tools (Voss et al 2015).

Currently, there is limited understanding of how paramedic students develop interpersonal and communication skills to support people with dementia and their families. The aim of this study is to understand the experiences of undergraduate paramedic students as they progress through their programme and explore the impact of teaching and clinical placements on the development of their clinical and interpersonal skills when supporting and caring for people with dementia and their families.

Methods

Design

An explorative interpretative phenomenological design was applied as both researchers are experienced healthcare professionals, and understood they may not recognise or be able to bracket all of their preconceptions during data collection and analysis (Zahavi, 2003). Therefore, the researchers acknowledged their experiences as a nurse and psychologist (JB), and a paramedic (MS) and from these perspectives interpreted paramedic students' experiences, thus working within the framework of interpretative phenomenology (Heidegger 1962).

Data were collected via focus groups with first and third year undergraduate paramedic students. A number of carefully planned group-based discussions were designed and a purposive sampling strategy was applied. Paramedic students' had a shared culture of university education and clinical experience, which fostered an environment where students were able to influence and be influenced by each other, as they would in the clinical setting (Hollander, 2004).

University Research Ethics Committee provided ethical approval. All participants provided written informed consent. Confidentiality within the group could not be provided, however confidentiality of discussions outside of the group was assured.

Participants

Paramedic students were recruited from one university in the South of England, students clinical placements occurred within one of two ambulance service providers. First (n=24) and third (n=33) year students completing a paramedic science degree, with male students (n=29) and female students (n=28).

Procedure

Focus groups were completed in January and February 2017 in university classrooms, and facilitated by the first author (JB) and observed by the second author (MS). A question route was applied to ensure consistency and comparability of data. Six focus groups were conducted; three with first year and three with third year paramedic students (refer to Table 1). A number of students self-disclosed they had a family member with dementia (n=18). Each focus group was audio recorded and transcribed verbatim.

Analysis

Inductive thematic analysis was applied within the framework of interpretative phenomenology, as thematic analysis is not a methodology, but an analytic method (Clarke and Braun, 2013). The process of thematic analysis as described by Braun and Clarke (2006) was adhered to: the data from each focus group was read and re-read to identify relevant text, initial codes were assigned to text extracts, from these codes broad themes were created, each theme and relevant codes were reviewed and refined, this process was repeated until clarity within and across themes occurred, themes were then named, and finally, the construction of relationships across and within themes.

Results

Three themes emerged from the thematic analysis: challenges of communication students' negative emotional response, and lack of social care and pathways. Themes and subthemes emerged from both first year and third year paramedic students; with the exception of the last theme that emerged only from discussions with third year students (refer to Table 2).

Challenges of communication

Paramedic students discussed the challenges of communicating with people with dementia, including how this impacted on understanding their needs, obtaining informed consent and how each person with dementia and their circumstances were unique, and therefore no generic rules could be applied.

Understanding their needs

Paramedic students expressed concerns regarding the needs of patients with dementia, as they were unable to gain sufficient information, such as a medical history or levels of pain, and felt this impacted on their clinical decision making, which 'can significantly disadvantage people with dementia because they cannot communicate, and things can be left or not noticed' (FG2, P2). A first year student reflected:

'It is challenging in a different way, because when you go to a complicated trauma you are focusing on medical problems, the challenging side is the medical side, but when you go to a patient with dementia the challenging bit during the visit is communication. It affects how we communicate with them, but also how they communicate with us' (FG5, P1)

Obtaining consent

Paramedic students discussed the fluctuating ability of patients with dementia to provide consent, 'some patients with dementia seem to have capacity and then five minutes later they don't' (FG2,

P4). Students' felt their programme placed an emphasis on informed consent, which created a barrier to supporting people with dementia. There was a general assumption among their paramedic colleagues (but not the students) that people with dementia do not have capacity to consent, but 'colleagues haven't actually established whether they do or not' (FG2, P6). A further difficulty was understanding which decisions people with dementia did and did not have capacity to consent to:

'Patients with dementia may have capacity for short term decisions, give consent for short term things, but it is hard to try and judge how much capacity they do have and if they fully understand what the decision involves.' (FG2, P5)

Each person with dementia and their circumstances are unique

Paramedic students agreed that due to the uniqueness of the impact of dementia on each person and their individual circumstances 'there are no set guidelines' (FG3, P6). Students reflected on the difference of learning about dementia and clinical skills:

'When you are doing splints, you think I have got this skill now, but with dementia there are so many different personalities in the world, you cannot generalise, you do not have this algorithm and this is how I deal with this situation, there is always going to be new ones, that will be idiosyncratic, that you are going to have to tailor your support again for that person.' (FG5, P7)

Limitations of learning this 'uniqueness' in the classroom was raised, 'there is only so much you can be taught in the classroom' (FG1, P9), and the importance of learning on the road:

'In the classroom it is just a generic overview of dementia, but it is not until you go out on the road and you see different people and how differently they present that you realise there is a broad spectrum of the disease.' (FG1, P1)

Students understood their development of learning clinical skills, through guidelines and protocols, however found learning how to support people with dementia led to conflicting advice:

‘Some colleagues have said they tell them (people with dementia) exactly what is happening, exactly what the situation is and why they are there. Whilst, others go along with the situation that the patient is seeing in their brain, and they might go along with that to make it easier to help them and find out what is going on and treat them accordingly. I don’t know whether that is the right thing to do or the wrong thing to do (FG1, P8)

Negative emotional response to dementia

Students felt dementia was sad and scary, and they experienced a feeling of helplessness when trying to provide support and care for people with dementia and their families. A number of students voluntarily self-disclosed information and incidents of family members with dementia.

Sad, scared and helpless

Students described being sad, afraid, and frightened by the impact of dementia, a first year student reflected:

‘I don’t know if people are afraid of it (dementia), I am certainly afraid of it, if I was ever diagnosed with it, I am just going to... I don’t know what I would do, I would freak out I think.

The prospect of it is horrifying actually.’ (FG4, P1)

Furthermore students discussed a sense of helplessness as they could only support the impact of dementia, such as a fall and not treat the dementia:

‘I guess part of you feels slightly helpless, because you come away from a call and you have treated the fall, you have treated something, but there is nothing you can really do for the underlying cause (dementia) that may have caused the fall in the first place.’ (FG5, P6)

Students also expressed how feeling helpless to support people with dementia and their families was a sad realisation for them:

‘It is sad, I think it is a bit doom and gloom, it is a bit of a sad realisation that there is only so much we can do and only so many referral we can make. It is almost like you want to say, this time we managed to get you help, but you probably didn’t.’ (FG2, P9)

Self-disclosure

Self-disclosure by students regarding family members with dementia occurred, and highlighted again how dementia impacts on the wider family:

‘My grandfather was diagnosed with dementia but, as soon as he was diagnosed my Mum didn’t want him to go out by himself, like walking the dog... I think that was quite debilitating for him, he was treated differently from the day he was diagnosed, and that wasn’t nice for him. He felt like he had lost his independence.’ (FG3, P1)

Lack of social care and pathways for people with dementia

Only third year paramedic students explored the lack of social care and pathways for people with dementia, and this could not be taught in the classroom:

‘I think it is the social side of it, the medical side we can fix, it is the social side of it, how do I sort this and I don’t really think that is something you can teach in a lecture that is something you have to learn through experience.’ (FG2, P7)

Students reported ‘surprise at the lack of social care’ and some people were living at home with ‘no actual social care in place or any NHS services to help them’ (FG1, P8), and this was a shock:

‘I think the social circumstances were a shock to me, the amount of people with dementia that don’t have anything in place and are living independently, but not living a good quality

of life. The fact this person has fallen through the net and no one has noticed they are struggling to cope on their own. I think that is the biggest shock.’ (FG2, P5)

The third year paramedic students discussed the lack of dementia pathways, whilst simultaneously acknowledging hospital was not necessarily a good pathway for a person with dementia:

‘I think it is quite frustrating there is not enough referral pathways, you can either leave them (people with dementia) at home, and if they have carers, then that is fine. But, if they live on their own, then that is not the best place for them, and with their injuries or illness, hospital is not the best place for them, and that is the only two options available to us (paramedics).’ (FG1, P4)

‘I think hospital is not the most appropriate place for people with dementia, because when they are used to their own environment they can manage to a certain degree in their own environment at home, and when you take them out of it, you always tend to see a rapid decline.’ (FG6, P2)

Discussion

During the first and third year of their programme paramedic students experienced a number of challenges when communicating with people with dementia, which impacted on their ability to adequately assess their health needs and gain informed consent for treatment and interventions. From this perspective students expressed negative emotional responses, such as sad, scared and helpless when trying to support people with dementia and their families. Only third year paramedic students expressed their shock at a lack of social care and support and pathways for people with dementia.

Challenges of communicating with people with dementia

Communication alongside patient safety and compassion is one of the crosscutting themes in all paramedic roles (Tavares et al 2016). However, in this study paramedic students reported challenges in communicating with people with dementia and understanding their needs. Other healthcare professionals such as experienced nurses specialising in dementia have also reported difficulty in understanding both the emotions and needs of people with dementia (Wang et al 2013).

Difficulties in communication between healthcare professionals and people with dementia may occur due to the task focused nature of these interactions. Task focused interactions inhibit the ability of healthcare professionals to understand and adapt to the needs of the person with dementia through open listening (Nichols, 1995). The development of open listening requires person-centred rather than task-orientated communication strategies with the avoidance of directive or instructive communication (Kitwood, 1997; Wang et al 2013); unfortunately this approach in itself is challenging in a crisis situation.

Person-centred communication education interventions have been developed and have been found to challenge the negative view of dementia by primary care healthcare professionals (Edwards et al 2014). However, to date these interventions have not been developed with or delivered to paramedics; therefore the development of robust and relevant education interventions for paramedic students and paramedics is required.

The 'uniqueness' of people with dementia was recognised by students in the current study and has been acknowledged by other healthcare professionals, alongside the need to tailor their care and support (Ducharme et al 2014; Stephan et al 2009). Tailored care and services are also important to support and address the uniqueness of family members (Ducharme et al 2014). The ability of healthcare professionals to tailor services is restricted as services are perceived as inflexible or even lacking (Stephan et al 2015; Ducharme et al 2014). This may explain why paramedic students working within these systems struggle to adapt to the 'uniqueness' of dementia.

Negative emotional responses to dementia

Paramedic students' negative emotional response to caring and supporting a person with dementia and their family is similar to other healthcare professionals' experiences. Healthcare professionals working in dementia services highlighted their distress and emotional struggle when identifying with family carers alongside their ethical duty to support people with dementia to live in a safe environment, and the need to internalise their actions with the belief they 'did the right thing' (Ducharme et al 2014; de Witt and Ploeg, 2016).

Paramedic students expressed their feelings of helplessness as they believed they were treating the impact of dementia, such as a fall, rather than addressing the underlying cause of dementia. The sense of helplessness was reinforced as students could not meet the expectations of family members. Previous work has acknowledged the high expectations of families when the resources available in a timely manner are restricted (Stephan et al 2015).

The development of new paramedic roles to specifically respond to the needs and challenges associated with the impact of dementia could reduce paramedic students' sense of helplessness. A recent exploration of the role of emergency medical services (EMS) to support people with dementia recommended new paramedic roles to respond to crises, urgent care needs, but also transitions between appropriate care facilities (Buswell et al 2014). However, concluded there was a lack of validated tools in EMS to assess and manage the needs of people with dementia (Buswell et al 2014). The emphasis on validated tools, although necessary, reinforces the focus on clinical skills rather than communication and interpersonal skills (Jackson, 2009, Ross et al 2015).

Lack of social care and pathways for people with dementia

The lack of social care and clear pathways for people with dementia has been acknowledged previously. British family members supporting and caring for a person with dementia described social and health care systems as a maze, which was difficult to navigate, access, and were limited,

with the added pressure of having to 'fight' for any provision of health and social care (Peel and Harding, 2014).

The need for clear social and healthcare pathways for people with dementia and their families is a global concern. However, Samsi and Manthorpe (2014) explored the term 'dementia care pathway' and found different interpretations and constructions, which ranged from management of the disease, manual of care activities, and how to 'walk with' the person with dementia. The interpretation of care pathways of the paramedic students was not explored, although the results of the current study support the recommendations of Samsi and Manthorpe (2014) of a wider system approach to support people with dementia and their families.

The development of a wider system approach may include the development of paramedics' skills to assess, treat and support people with dementia in the primary care setting. The need to adapt to this approach is not unique to the UK. Paramedics and social workers in the State of Idhao discussed a lack of social care and support for families with a member with dementia, and paramedics requested further training and education in dementia and de-escalation strategies (Stolp et al 2016). In Canada the role of the paramedic has been conceptualised to include six elements: clinician, team member, health and social care advocate, educator, reflective practitioner and professional (Travares et al. 2016). The educator role is important for the provision of information for families of people with dementia as may reduce the number of emergency calls (Stolp et al 2016). Paramedic students in the current study had begun to develop their skills as advocates for people with dementia by completing referrals for them to access social care, whilst simultaneously reflecting on their practice and the realisation that sometimes there is not enough support for people with dementia to remain living well and independently at home.

Limitations

A limitation of the current study was the involvement of students from only one university, although their clinical placements were across two different ambulance service providers.

A major consideration that impacts on the discussion of this paper is the lack of paramedics in the majority of studies that have explored the views of people with dementia, their family members and healthcare professionals in community settings (Edwards et al 2014; Stephan et al 2015; Ducharme et al 2014; de Witt and Ploeg, 2016).

Conclusion

The development of paramedic specialist roles in dementia are being developed and implemented. The importance of skilled university lecturers and placement educators knowledgeable in dementia is also essential to enable the development of interpersonal and communication skills of paramedic students and to empower them to support and care for people with dementia and their families.

Finally, there is currently a lack of research involving paramedics, which impacts on the robust development of education and training to support the development of the knowledge, clinical and interpersonal skills to support and care for people with dementia and their families.

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Table 1: Overview of focus groups

Focus Group	Students' Year of study	Participants	Male (Female) participants	Self-disclosed family members with dementia
1	3	10	4(6)	3
2	3	11	6(5)	3
3	1	8	6(2)	3
4	1	9	3(6)	4
5	1	7	4(3)	2
6	3	12	6(6)	3

Total number of participants (n=57)

Table 2: Emergence of sub-themes from each focus group

	Challenges of communicating with people with dementia			Negative emotional response to dementia		Lack of social care and pathways for people with dementia	
Focus Group	Communication with people with dementia	Obtaining consent	Each person with dementia and call is unique	Sad, scared and helpless	Self-disclosure	Social Care	Pathways
1 3 rd year students	X		X	X	X	X	X
2 3 rd year students	X	X	X	X	X	X	
6 3 rd year students	X	X	X	X	X		X
3 1 st year students	X	X	X		X		
4 1 st year students	X		X	X	X		
5 1 st year students	X		X	X	X		